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Ethics briefings

Veronica English, Gillian Romano-Critchley, Ann Sommerville and Jessica Gardner *Medical Ethics Department, British Medical Association*

Conjoined twins

On 8 August 2000 conjoined twins, known as Mary and Jodie, were born to Maltese parents at St Mary's Hospital in Manchester. Cases of conjoined twins are rare, affecting around one in every 100,000 live births. Mary and Jodie were joined at the lower abdomen. Jodie, the stronger twin kept Mary alive since Mary's vital organs were too damaged to sustain her. Had she been a singleton, Mary would not have survived. Mary's brain was described as having only primitive function whereas Jodie's appeared normal. They shared Jodie's aorta so that Jodie's heart supplied blood to Mary, which was oxygenated in Jodie's lungs. In sustaining Mary's life, considerable strain was exerted on Jodie's heart which, according to expert opinion, would fail within three to six months, resulting in both their deaths. To withdraw that life-line through separation would inevitably lead to Mary's death but give hope of survival to Jodie. The parents, however, said they could not consent to separation if this would result in Mary's death. The twins were equally precious to their parents who felt that it was "not God's will" for them or anyone to choose death for one. They could not agree to kill one even to save the other. Furthermore, it was uncertain that Jodie would survive surgery. If she did, she would require considerable care and further operations to build a vagina and anus. She might never be able to walk and her parents were uncertain that they would be able to look after her.

Doctors sought a declaration from the High Court as to whether the operation was lawful in the light of the parents' refusal to consent.[1] The doctors considered that they should try and save one twin rather than allowing both to die. The High Court authorised the doctors to proceed, overruling the parents' refusal. It was considered by the judge, Johnson J, to be in Mary's best interests for the operation to proceed even though it would lead to her death. There was no means of telling whether or not she was in pain and the judge considered that the few months of life remaining would be worth nothing to her. To prolong her life further would be seriously to her disadvantage. The operation was compared to the withdrawal of life-sustaining treatment.

The parents appealed against the decision but the Court of Appeal also considered that overriding the parents' refusal was appropriate in this extreme case.[2] Although the decision of the lower court was upheld, the Court of Appeal's reasoning differed. Ward LJ emphasised that the case seemed to have no obviously "right" answer and whatever judgment was given, some would applaud it and some be offended by it. The Appeal Court did not consider that Mary's life was not worth living and would mean nothing to her. Instead, it emphasised that the principle of sanctity of life was so enshrined in English law and commanded such respect that it must be accepted that every life has inherent value and dignity. The decision to authorise the operation that would kill Mary was lawful in the best interests of Jodie under the principles of family law, and was justified under the criminal law through the defence of necessity. The fact that Mary would be killed by the operation could have been fudged by immediately connecting her to a heart and lung support machine once she was separated from Jodie but the court said that this "would make a mockery of law and medicine to escape some of the difficulties in this case". The judges repeatedly emphasised "the unique circumstances" of the case and warned that their ruling should never be used to justify euthanasia.

The court faced the conflicting and irreconcilable rights of two children. Both had an inherent right to life, yet saving one entailed killing the other. It chose to establish what would be the least detrimental choice, balancing the interests of one child against the other. It was argued that the fact that Mary was "killing" Jodie provided the legal justification for the doctors to come to Jodie's assistance by carrying out the operation. The court asserted that Mary must be regarded as a human being in law. Surgery was a positive act to kill her, and her death was intended by the doctors, but the court ruled that in the very specific circumstances of the case, the doctors had a defence of necessity to the charge of murder.

This justification has not normally been available as a defence to murder. In 1884, the case of *Dudley and Stephens* considered two shipwrecked mariners who killed and ate a cabin boy after 17 days adrift at sea.[3] The boy was very ill and would not have survived. If the mariners had not killed him, all three would have died. The mariners were found guilty of murder since the court took the view that there can be no defence of necessity where the act is to preserve one's own life. Indeed, there are circumstances in which there may be a duty to sacrifice it. It raised the question of who should decide which person should die if a similar case were ever to occur. It is arguable that this is the same conflict that the courts faced in relation to Mary and Jodie. Such cases highlight the dilemma between the desire to reaffirm the principle of sanctity of human life and the widely felt compassion for people placed in an extreme situation. In the twins' case, the court decided it was unable to choose definitively between the arguments that it would be immoral to kill Mary to save Jodie and that it would be immoral not to save Jodie if she had a good chance of survival. Instead, it chose to highlight the exceptional circumstances of the case, distinguishing it from *Dudley and Stephens* and the traditional policy considerations to which this kind of dilemma gives rise. Referring to Mary, Ward LJ emphasised that: "the sad fact is that she lives on borrowed time, all of it borrowed from her sister. She is incapable of independent living. She is designated for death." The operation to separate the twins came to an end at 5 am on 7 November 2000, resulting in Mary's death and Jodie's survival.

(See Editorial: Imposed separation of conjoined twins–moral hubris by the English courts? page 2.)

Right to Life

The months leading up to the UK's implementation of a new Human Rights Act were filled with speculation about the act's effect on medical decision making. The act incorporated the bulk of the European Convention on Human Rights into UK law, giving citizens the opportunity to pursue rights such as the right to life, to privacy and to be free from degrading treatment, in the domestic courts.

In a case heard just days after the act's implementation, the High Court was asked to consider applications to withdraw artificial nutrition and hydration from two women who were in a persistent vegetative state (PVS).[4] Over the last decade, the UK courts have made a number of declarations that it is lawful to withdraw artificial nutrition and hydration from patients in PVS. "Pro-life" groups, however, speculated that the right to life under the Human Rights Act would challenge this common law position. The right encompasses a clear obligation to refrain from taking life intentionally, and a positive obligation to take adequate and appropriate steps to safeguard life.

The court held that withdrawing or withholding potentially life-prolonging treatment in cases such as these did not constitute an intentional deprivation of life. It also held that the positive obligation to safeguard life was discharged where the responsible clinical decision was that the provision of further treatment was not in the patient's best interests. Since it was agreed that it was not in the best interests of either patient to continue artificial nutrition and hydration, the court granted declarations in respect of them both.

Embryo research

Embryo research was the subject of debate around the world at the end of 2000. The ongoing debate about the status of the embryo was given added stimulus by growing excitement about the potential use of human embryonic stem cells for the development of tissue for transplantation. This has once again brought into sharp focus the diverse approaches to embryo research across Europe.

The UK was one of the first countries to introduce legislation setting out a regulatory framework for infertility services. The Human Fertilisation and Embryology Act 1990 permits embryo research up to 14 days after fertilisation with strict safeguards. The act restricts embryo research to a limited number of purposes. Proposals to amend this list to include research using human embryonic stem cells for the development of tissue for transplantation were put forward in August 2000.

Legislation in some other countries, such as Spain and Sweden, has taken a similar approach to the UK, permitting embryo research subject to strict safeguards, whereas in countries such as Germany and Austria legislation prohibits all embryo research. Not all countries have legislation in this area and some countries have been going through the process of drafting and debating laws.

In the Netherlands, draft legislation was published on 26 September 2000. The bill would permit research involving human embryos left over from in vitro fertilisation (IVF) treatment, subject to monitoring and control. It includes a list of purposes for which research may be carried out; these include "transplantation", specifically to address developments in embryonic stem cell research. Although the bill includes provision for the creation of embryos in the course of research, it is proposed that this should be subject to a three-year moratorium.

Declaration of Helsinki

In October 2000, the World Medical Association (WMA) finalised its revision of the Helsinki Declaration. This key guidance has helped define the ethics of research on humans since the 1960s and this is its fifth revision. The most contentious aspect of the revision has been defining the standard of treatment that should be assured to patients participating in research, particularly in developing countries. The WMA has now made clear that the use of placebos would generally be unethical in research involving diseases that already have effective treatments. Previously, its views on placebos had been more open to interpretation. The revised declaration states that any new treatments should be tested against the best current treatments. Placebos can be used, however, where no proven treatment exists. The new declaration is available on the WMA website (www.wma.net).

References

1 Central Manchester Healthcare Trust v (1) Mr & Mrs A (2) A Child (By the Official Solicitor the Guardian ad litem) 25 August 2000 (unreported).
2 Re A (children) TLR 10/10/2000.
3 Dudley and Stephens (1884) 14 QBD 273.
4 NHS Trust A v Mrs M: NHS Trust B v Mrs H (2000).